Antenatal Results & Choices in 2022-23

Impact Review

arc-uk.org
Helpline 020 7713 7486

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> The support I received was outstanding... I would have really struggled without it. Even recently I have been in touch about a new pregnancy and they have been understanding and offered support if I need it... I would advise anyone who has received bad news during a pregnancy to make contact as the support they will receive will be a lifeline during a dark and difficult time.
>
> Parent survey 2023

INTRODUCTION

Welcome to Antenatal Results and Choices' (ARC) Impact Review for 2022/23. We are proud to share with you how our work makes a difference to the parents and healthcare professionals we support, and to let you know about our ambitions and plans for the future.

ARC operates in a complex, ethically-charged area of healthcare, which makes it difficult to quantify our impact. A big thank you, therefore, to everyone who took the time to take part in our comprehensive survey this summer.It is your responses that have helped us better understand and demonstrate the difference we make. This in turn, has helped to guide our strategy and development goals for 2022-25 which focus on increasing our reach to parents and professionals across the UK, particularly in more disadvantaged and isolated communities.

Ongoing contributions from our fantastic supporters and a very generous investment from a major donor means that we can be ambitious about the next phase in ARC's development. As a result, we have an expanded team, with two new Coordinators in England and our first Coordinator in Northern Ireland. By considering our survey feedback and engaging sensitively with ethnically- and regionally- diverse organisations and users, we can plan how better to serve these communities. We can also afford to subsidise our highly-regarded professional training programmes to ensure a wide range of frontline specialists can attend despite limited NHS resources.

In 2023, ARC reached the milestone of 35 years as a registered charity! We marked this with a brand refresh, a redesigned and better functioning website and a programme to raise our profile and improve accessibility. Since our foundation in 1988, we have seen huge changes in the antenatal testing landscape, alongside some eventful times for us as a charity (see p 6).

However, what has not changed at all is the psychological impact that unexpected antenatal test results have on parents; the intense shock of being told that baby is not developing as expected and the life-changing decisions that may follow. Nor does it get any easier for professionals to give difficult news, for which expectant parents are never truly prepared. This is why ARC exists and why we are passionately committed to ensuring that everyone who might need our specialist support can access our services, whoever and wherever they are.

Thank you so much for your support.
Jane Fisher, Director

ARC'S YEAR AT A GLANCE

The difference we made in 2022-23

Our website's resources reached over **127,000** people.

1,039 healthcare professionals (particularly midwives, students and sonographers) attended our training programme, online and face-to-face.

Helpline (calls and emails) were requested **6,640** times.

664 new parents were given access to our Peer Support Network – **19** volunteers with lived experience of specific diagnoses and child bereavement.

We relaunched our face-to-face parent support meetings for **69** parents in **7** locations: Birmingham, Liverpool, Southampton, Sheffield, Exeter, Leeds and London.

Social media content appeared on peoples' screens **744,707** times and we attracted **1,136** new followers.*

* Facebook, Twitter and Instagram combined. These impressions were largely organic, with a small number of paid advertisements.

We reached over **3,000** healthcare professionals via talks and stands at **10** national conferences and forums (including the Royal College of Midwives' conference in Newport, the British Fetal Maternal Medicine Society Meeting in Birmingham, the NHS Genomics Summit in London and the National Bereavement Care Pathway Launch in Edinburgh).

5,151 bereaved parents are now registered on our forums – safe spaces for parents to share experiences and coping strategies.

The impact we had

Our resources...

94% of parents surveyed said their expectations were 'Exceeded' or 'Met' by our services

"I accessed ARC's website the moment our baby was given a fatal diagnosis in March '23. The website became my lifeline, providing me with support, comfort, reassurance... and provided useful resources I gave to my parents and in-laws to read." **ARC parent survey 2023**

Our professional training...

99% of professionals surveyed would recommend ARC to others

"Excellent training overall, acknowledgement of the impact on the parents, the emotional burden of decision-making on a family." **ARC professional survey 2023**

Our peer network and parent communities...

70% Nearly 70% of parents surveyed accessed the sustained support of our forums, meetings and voluntary network

"This was the best support I received. It was such a sad and sensitive time and a lifeline to feel safe and have a regular contact with a volunteer. They were very well trained, said really comforting things that I really needed to hear at the time and helped me heal and move forward." **ARC parent survey 2023**

Our specialised support...

"ARC is the only charity in the UK who offer support and counselling to parents who receive complex fetal diagnoses in pregnancy and they face difficult decisions. It is a small charity which has a major impact on lives of many people." **ARC professional survey 2023**

1988-2023: 35 YEARS AND COUNTING

28th August 1988:
Launched as 'SATFA' (Support After Termination For Abnormality') by a group of healthcare professionals and bereaved parents who recognise that the practical and emotional needs of bereaved parents are not being met.

1993 As we take more requests for support at the point of prenatal diagnosis, we change our name to 'Support Around Termination For Abnormality'.

ARC
Antenatal Results & Choices

1998 Final name change to Antenatal Results and Choices (ARC) to take account of the increase in demand for information and support on all aspects of antenatal screening.

2003 The UK National Screening Committee takes responsibility for overseeing the implementation of standardised national antenatal screening tests offered to all women.

2004
Rapid molecular testing is routinely offered after CVS or amniocentesis, reducing waiting time from 10 days+ to 72 hours.

2010 A national ultrasound screening 'menu' of conditions is introduced for the 20-week scan.

2012 Non-invasive Prenatal Testing (NIPT) for Down's syndrome is available privately in the UK.

2013 25th Anniversary celebrated with our 'Put the kettle on' campaign, raising over £40,000!

Put the kettle on for ARC

2014
Coordinator in Scotland appointed, with Wales following in 2021 and Northern Ireland in 2022.

2015 The first trimester combined screening test for Down's syndrome, Edwards syndrome and Patau's syndrome is offered to all pregnant women in England.

2018 30th anniversary conference theme, 'Risks: 'Results and Raised Anxiety: Current Issues in Antenatal Screening'. Attendees learnt about latest developments in prenatal whole genome and exome testing, fetal MRI scanning and new first trimester screening techniques.

2020 NHS introduces prenatal genomic sequencing to help improve diagnosis of rare genetic conditions in pregnancy.

We see a marked increase (27%) in engagement from families and professionals struggling during the Covid-19 pandemic, and launch our online training and case cafes.

2021 NIPT is incorporated into the existing NHS England antenatal screening pathway for Down's, Edwards' and Patau's syndromes.

2023 By our 35th birthday in 2023, we're now a team of 12 staff, 5 trustees and 19 peer support volunteers!

Antenatal Results & Choices

PARENT SERVICES: IMPACT AND IMPROVEMENT

Impact in 2022-23

Reasons to seek ARC's help in 2022/23 varied widely, as always - from needing help understanding complex information and unexpected news from scans or screening test results, through to support during the decision-making process after diagnosis or bereavement following a termination for medical reasons (TFMR).

With an increased number of helpline staff, we are in a much better position to respond to requests for expanded support. As well as our new evening helpline offer, we've:

> "I valued the information on the website immensely in the early days and now find the face-to-face meetings a useful place to help me process my experience. I also like hearing other peoples' stories. It makes me feel less alone and helps me contextualise what happened."
>
> Parent survey 2023

- Translated our two most-requested parent publications, 'Supporting you through your pregnancy' and 'Ending a pregnancy after prenatal diagnosis', into five languages (Bengali, Polish, Punjabi, Romanian and Welsh) which are available online.

- Published our first resources specifically for LGBTQ+ parents, available online.

We also relaunched our much-requested face-to-face parent support meetings, which had been paused during the Covid-19 pandemic. Specifically for parents who have been through a termination of pregnancy following a prenatal diagnosis, the sensitively facilitated day is spent sharing experiences, coping strategies and hopes for the future. Six support meetings (in Birmingham, Liverpool, Southampton, Sheffield, Exeter and Leeds) were funded by a National Lottery Community Fund grant and publicised via social media and our mailing list. The impact of these was immediately clear in parent evaluations:

"What I wasn't expecting was to come away from the meeting feeling positive - and for that feeling to continue into the week. I felt that I wasn't alone and that it was okay to think about my baby and acknowledge that I had a son."

We are now planning additional sessions across the UK, including London, Newcastle and Cardiff.

We know how valuable real life stories are for parents who can often feel vulnerable and isolated, and we are very grateful to the families who have so generously allowed us to share their experiences - like Sam and Kate. We have been heartened by the number of parents reaching out to share their story and will be publishing more online in 2023-24.

We chose an abortion for our daughter Rosa. She had a very serious heart problem, which would have meant a short life of pain and no realistic prospect of a cure. When we were told the awful results of the 20-week scan, we had good access to medical advice. We asked lots of questions to understand our options. Sam called the wonderful ARC helpline and wailed incoherently at the lovely lady at the end of the line and we spoke with family and friends. We felt our assessment of whether abortion was the right decision for Rosa was based on the best advice. We don't like the decision we took, but do like that it made things better for Rosa.

We chose a TFMR so we could see and hold Rosa. We were surprised how much of a little person she was. She had all her tiny fingers and toes, and looked (mostly) like she was just having a peaceful snooze.

The TFMR was awful, but we knew what to expect. The time after the abortion is in many ways harder. The void of Rosa's absence and returning to normal life are not happy bedfellows. We're lucky to have plenty of people to talk with. Some have simply listened; others talked of their experiences; and others gave snippets of advice. The best advice was blunt: prepare for the long haul.

The core of this grief is a trauma we can't solve, and probably won't. It's tiring, frustrating and unfair. We use it as a reminder that Rosa was real, we loved her, and did the very best we could for her.

The friendly and rational ARC helpline was enormously helpful in dealing with the agony of Rosa's TFMR, such that we were able to prepare mentally for trying for another baby. The helpline was then invaluable to us in handling the stresses of trying to conceive and Isobel's foetal scans. Rosa's little sister Isobel is now here and healthy, and we are profoundly grateful for ARC's support.

Sam and Kate

This is a shortened version of Rosa's story. To read stories in full, go to 'Your Stories' on the ARC website.

Photograph of Sam and Kate © Sophie Liffen Photography.

Ambitious about our impact

Whilst responses from our 2023 parents survey were almost uniformly positive, it is clear that ARC is not as visible or as accessible as we could be to families from more ethnically diverse backgrounds and those living in disadvantaged communities. We are involved in a number of initiatives to ensure that we develop in this area. For example, our Coordinators were given useful perspectives on integrating service provision into diverse communities and the value of co-partnering, when attending a 2022 study day run by Child Bereavement UK, "Understanding faith and bereavement – the Islamic perspective" and the Black Maternal Health Conference in 2023. It is critical that our services are fully inclusive and we are considering how best to expand our demographic reach in the new financial year with a pilot project with community groups in East Lancashire.

Our community strategy includes a commitment to supporting Dr Michelle Peter with her fellowship PhD research project, 'Genetic Screening and diagnosis during pregnancy: What are the experiences of Black women and their families?' ARC will support Dr Peter in an advisory and funding capacity, heading the Patient and Public Involvement Advisory Group. As well as helping to disseminate research findings, we will consider how outcomes from this project can help us shape services from Black and other ethnic minority communities.

Our new SMS helpline service, and further translations of our publications into Arabic and Urdu, highlight our resolve to improve ARC accessibility across all communities in 2023-24.

The importance of connection with other parents was a key theme of our survey, with many mentioning ARC's peer support volunteers with lived experience of pregnancy bereavement, and the podcast Time to Talk TFMR.

Launched by Hayley Manning, Time to Talk TFMR is supported by us. Hayley had a TFMR following her baby Luna's diagnosis of Turner's Syndrome in 2017. Here she explains her personal journey:

In 2019, I decided to volunteer as an ARC parent support volunteer. It had helped so much shortly after my TFMR to be able to speak to another woman who had also decided to end her pregnancy. It was a relief to speak to someone not only who had gone through this, but here she was, several years later, surviving and thriving. I wanted to be able to offer this hope to others.

Most women I speak to are in so much shock. I can hear it in their voices – strained, breathless. My heart breaks for them, and I remember myself in those early weeks and months. For me to say 'I recognise these feelings, I felt them too. It is the hardest thing I have ever had to go through, and I have survived and I am happy again', I hope this gives them trust in themselves that they too can work through this.

There is a dance between allowing the feelings, all the messy, ugly feelings – being able to say them out loud, and then recognising you are living through these feelings. Women are so resilient, we definitely do not recognise this enough in ourselves. We need to be able to share and lean on one another, and the ARC parent support network is a way of doing this, it is vitally important.

I have gone on to start the Time To Talk TFMR podcast, which is an extension of what my volunteer work at ARC does and a way of reaching more people. We have been producing regular episodes since the beginning of 2021 and have over 50,000 downloads, with hugely positive feedback from our listeners.

Hayley

You can read Hayley's full story on ARC's 'Your Stories' website page, and download Time to Talk TFMR episodes by going to https://talktfmr.buzzsprout.com/

ARC IN NORTHERN IRELAND

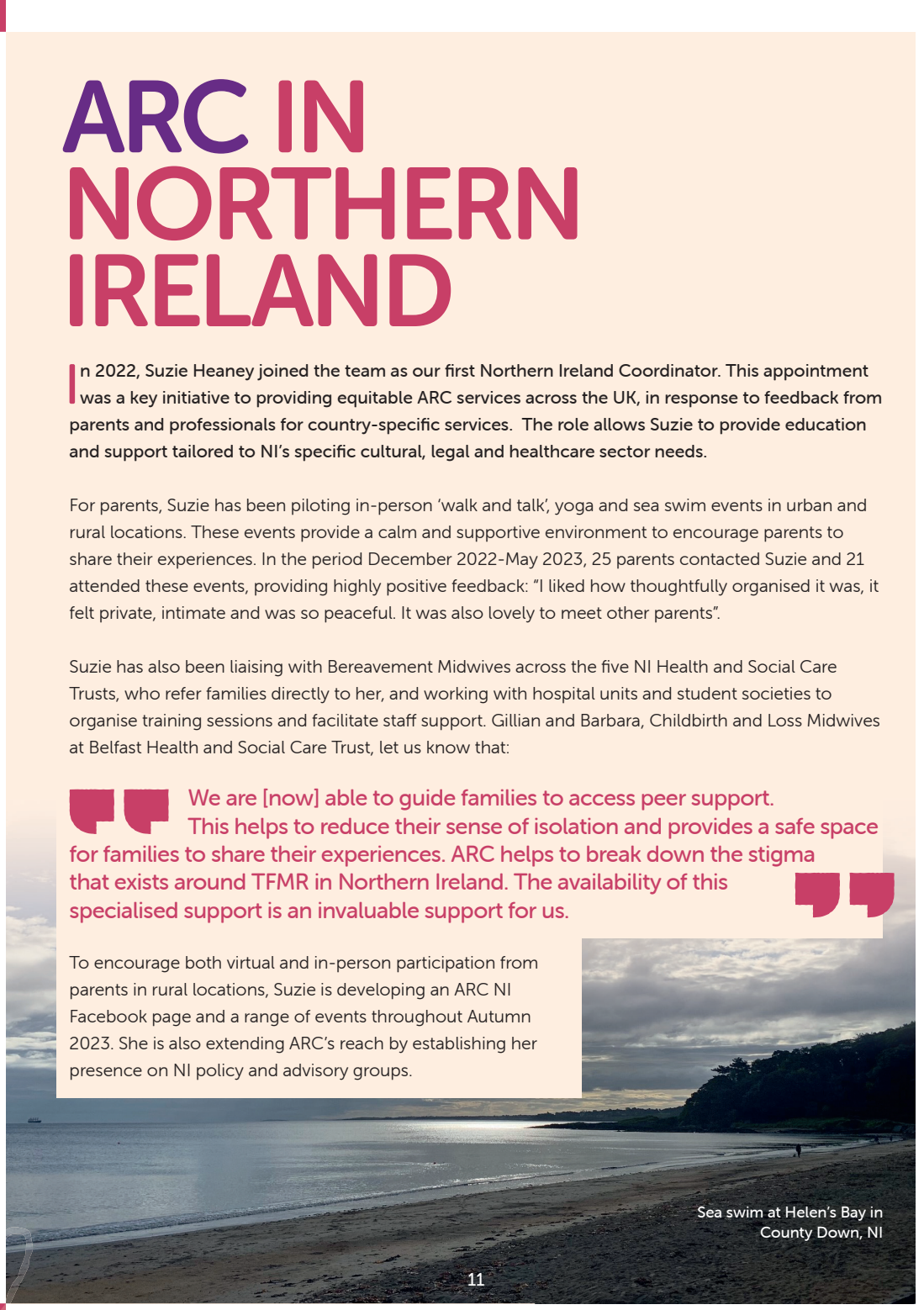
In 2022, Suzie Heaney joined the team as our first Northern Ireland Coordinator. This appointment was a key initiative to providing equitable ARC services across the UK, in response to feedback from parents and professionals for country-specific services. The role allows Suzie to provide education and support tailored to NI's specific cultural, legal and healthcare sector needs.

For parents, Suzie has been piloting in-person 'walk and talk', yoga and sea swim events in urban and rural locations. These events provide a calm and supportive environment to encourage parents to share their experiences. In the period December 2022-May 2023, 25 parents contacted Suzie and 21 attended these events, providing highly positive feedback: "I liked how thoughtfully organised it was, it felt private, intimate and was so peaceful. It was also lovely to meet other parents".

Suzie has also been liaising with Bereavement Midwives across the five NI Health and Social Care Trusts, who refer families directly to her, and working with hospital units and student societies to organise training sessions and facilitate staff support. Gillian and Barbara, Childbirth and Loss Midwives at Belfast Health and Social Care Trust, let us know that:

> We are [now] able to guide families to access peer support. This helps to reduce their sense of isolation and provides a safe space for families to share their experiences. ARC helps to break down the stigma that exists around TFMR in Northern Ireland. The availability of this specialised support is an invaluable support for us.

To encourage both virtual and in-person participation from parents in rural locations, Suzie is developing an ARC NI Facebook page and a range of events throughout Autumn 2023. She is also extending ARC's reach by establishing her presence on NI policy and advisory groups.



Sea swim at Helen's Bay in County Down, NI

PROFESSIONAL SERVICES: IMPACT AND IMPROVEMENT

In 2022-23 the arrival of two new Coordinators meant that we could expand our training programme, delivering more sessions equitably across the UK. Our training provides all antenatal professionals – midwives, doctors, sonographers, genetic counsellors and students - a holistic understanding of the parent experience from the moment they receive unexpected news. We were, therefore, delighted to see that in our 2023 survey, 88% of professionals said that they signpost their patients to ARC's services, whilst 75% have attended ARC training in some form. We always monitor and learn from feedback to shape our training offer.

> Thank you for the accessible resources, they make such a difference to the care provided to women and their families and ensure good quality information is given to each person.
>
> **Professional survey 2023**

This year, we prioritised a return to face-to-face training, with 55 in-person sessions and 24 online programmes. Although virtual training enables a wider reach – our informal online 'Case Cafes' continue to be very popular - it is clear that following the pandemic, professionals preferred an in-person opportunity to discuss sensitive topics and meet with peers to discuss particular challenges. Feedback from the 79 sessions held (attracting 1,039 attendees) and survey results were unequivocally positive. For example, Rebecca Drake, a Fetal Medicine and Antenatal and Newborn Screening Midwife at Norfolk and Norwich University Hospitals, said that attending our London-based training allowed her "more insight into what families may experience following unexpected news or results in pregnancy... It was also great to network with other professionals. Dr Mariya Kalgo from the Royal Wolverhampton NHS Trust also shared her perspective on our services, from the point of view of a Consultant working in Obstetrics and Fetal Medicine:

'I am a huge fan and beneficiary of ARC. I have attended their training sessions and case cafes. TFMR is still sadly a taboo subject but I am grateful for a charity like ARC that I can refer my patients to for an informal discussion around the complexities of their diagnoses to help them make the best decision. Their training and leaflets have helped me to offer better counselling to my patients and colleagues alike.

The case cafes with fellow professionals are an excellent debriefing session for a job that is sometimes emotionally demanding. I cannot recommend them enough.'

Mariya

In Wales, our Coordinator Miranda delivered training both in-person and online. ARC provided free training for midwifery students in Cardiff, Swansea and Bangor as an incentive - these sessions alone attracted 300 students, nearly a quarter of our annual training participants! In Scotland, Coordinator Karen facilitated nine parent support meetings in Glasgow, and peer support groups in both Glasgow and Edinburgh. She also had a key role in the introduction of the national bereavement care pathway and her workshop at the launch event in Edinburgh proved highly popular.

We also responded to requests from professionals to see filmed interviews with parents describing their experience of prenatal diagnosis and ongoing care. In May 2023 we commissioned Big Picture Charity Films to film four individuals and one couple narrating their stories, from the type of support they were given at the time of diagnosis to the care and choices provided around their termination; advice they would give professionals, and how has ARC helped them. The results are incredibly moving and provide compelling content for our professional training sessions. We are so grateful to the parents involved: Claire, Karen, Michaela, Hannah, Alex and Nathalie.

Ambitious about our future

"The service I received [with ARC] was fantastic and cannot be improved. However, had I not been given a leaflet I would not have known about them! So definitely making [ARC] known - their details should be displayed in every early pregnancy/maternity unit in every hospital!"

To ensure that ARC is truly a national charity, we aim to build on the current professional offer to ensure that all professionals have access to training and feel confident signposting parents to our helpline. As noted in parents survey feedback (above), there are some areas of the UK where NHS providers are not aware of our resources and parents tend to 'stumble across' ARC themselves. This means that too many people risk missing out on access to our services when they most need them. To ensure we increase professional awareness of ARC and encourage broader geographic impact, we will:

- **Subsidise professional training in areas of the UK that do not traditionally refer to us**. This will start with the North East of England, the Midlands and Peterborough. We start with a tailored workshop for fetal medicine staff in Newcastle in Autumn 2023.
- **Run a free online conference in September 2023**, with input from academics, policy leads, and clinicians from across the UK. The programme includes the impact of NIPT in Wales; fetal medicine services in Northern Ireland; high-quality care after pregnancy/baby loss in Scotland, and improving equity of care in England.
- **Offer travel grants to professionals traveling to training from remote locations**
- **Increase availability of our free publications to all hospitals.**

ARC'S IMPACT ON THE SECTOR

Two core components of ARC's mission are ensuring that parents have access to non-directive information and support through antenatal testing and its consequences to help them to make the choices that are best for them in their individual circumstances. In 2022-23 we started two important collaborative projects to further these aims:

1. Guidelines for professional care after antenatal diagnosis

While much has been done to quality assure care through antenatal screening, when a diagnosis is made, outcomes are much more variable. To help share good practice and increase consistency ARC has set up and is leading an expert working group with 18 members, which includes leading clinicians, specialist midwives and policy leads. We are currently drafting a consensus document that we are confident will help all units provide high quality care, whatever decisions parents make after prenatal diagnosis. This will be ready for publication by the end of 2023.

2. Prenatal diagnosis, disability and reproductive choice

ARC is absolutely committed to ensuring that expectant parents are able to make their own informed choices through screening and diagnosis. However, it is also important that antenatal screening is framed in a way that is respectful and sensitive to those living with screened for conditions and their families. We feel strongly that conditions need to be described in a balanced way and that parents should not feel that they are judged, whatever decisions they make. ARC organised a symposium in December 2022 that brought together charities supporting people with genetic conditions, disability rights activists, academics and pro-choice advocates, to develop a set of principles which will underpin an ethical antenatal screening and diagnostic service. We hope to publicise this work in early 2024.

A VERY BIG THANK YOU

ARC's impact would not be possible without the continued support from our wonderful supporters and generous donors.

Alongside the major gift that enabled us to develop an ambitious 2022-25 strategy, regular giving has supported both our core activity and project work. In the last 12 months, we've seen innovative fundraising from individuals like Reeya, pictured, who ran the Great North Run and the Leciester Half for us in 2022, Gail and Ron who asked for donations instead of wedding gifts, charities like Fairy Water Trust who donated specifically to our Welsh and London training activity, and organisations like SoftCat PLC, who fundraised for us as part of their Corporate Giving Programme. We are hugely grateful for everyone's generosity – we do not receive statutory or NHS funding, so these individual donations make everything we do possible.

We are committed to building a strong and sustainable future for ARC. If you would like to support us, whether that be with a fundraising event, regular giving, a grant or corporate partnership, please get in touch with Katy@arc-uk.org.

We end with an extract from Chloe and Tom's story about their baby Noah, as testament to the value of our resources:

"We spoke to ARC who helped us understand different testing and prognosis and how to get second opinions, and they talked me through medical termination as no one else seemed to want to give me that home truth! They also helped us prepare questions for the doctors and ensure we understood everything... After a lot of thought, we decided to terminate before he passed away to save his suffering... to anyone else going through this all I can say is educate yourself... ask for second opinions, ask for them to explain it again, speak to ARC. And always feel you have a choice."

Chloe and Tom

Chloe and Tom's story is available in full on ARC's Your Stories website page

ARC's national helpline

Want to talk? **Call 020 713 7486** or email us at **info@arc-uk.org**

Antenatal Results and Choices

12-15 Crawford Mews, York Street, London, W1H 1LX

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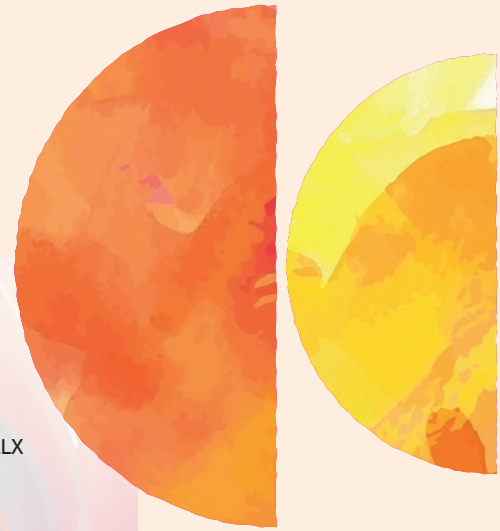

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